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ABSTRACT

Intended for educators, the booklet presents information on Tourette's Syndrome (TS), an inherited neurological disorder characterized by involuntary multiple motor and vocal tics. The first section describes Tourette Syndrome--its causes, symptoms, and treatments. In the second section, suggestions are provided to help teachers and school personnel adapt to the specific needs TS children may have including dealing with tics, dealing with writing problems, dealing with language problems, and dealing with attention problems. The final section suggests answers to eight questions that teachers frequently ask when dealing with children with TS and their families. Questions cover finding time to implement accommodations, identifying the child with TS, the prognosis for a child with TS, effects of medication, and sources of more information. Ten additional resources are listed. (DB)

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AN EDUCATOR'S GUIDE TO TOURETTE
SYNDROME

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AN EDUCATOR'S GUIDE TO TOURETTE SYNDROME

Dear Educator:

The fact that you are reading this pamphlet on Tourette Syndrome (TS) means that you probably have had some contact with a child in your school or classroom who has been diagnosed with this disorder, or, perhaps you have heard something about the disorder in the media and are wondering if a child you know might have TS. In either case, by becoming better informed, you have taken a very important step in the total care of that child. The treatment of this complex, perplexing neurological movement disorder requires a strong team approach. The parents, child, medical professionals and especially the teacher, all working together, can effectively ensure that children with this disorder can live up to their fullest potential as individuals.

While you may not know a great deal about TS, as you read this booklet, you will undoubtedly see that the skills and knowledge you have gained when integrating those children with chronic medical problems, physical differences or other types of disabilities into your classroom, also apply when helping children with TS. This publication aims to provide specific information about TS and to guide you in choosing your approaches to educating these children.

Three sections are presented. The first describes Tourette Syndrome -- its causes, symptoms and treatments. In the second section, suggestions are provided for teachers and school personnel for adapting to the specific needs TS children may have. The final section suggests answers to questions that teachers frequently ask when dealing with children with TS and their families.

Medical science is hard at work unraveling the puzzle of Tourette Syndrome. New understanding of its cause and new methods of treatment are being researched. The Tourette Syndrome Association can always provide you with the most current information on TS.

Thank you for your interest and caring. We hope you will share this information with your colleagues and school administrators.

Tourette Syndrome Association, Inc.
42-40 Bell Boulevard
Bayside, New York 11361
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A POSSIBLE SCENARIO

There is a child in your class who is very perplexing. She is bright, friendly, anxious to please, generally well-behaved and polite. However, for no apparent reason, she disrupts the class with snorting noises. She also blinks her eyes constantly, even though the eye doctor says she doesn't need glasses. She also persists in jumping around in her seat. You have spoken to her and her parents about her behavior, but she has persisted. You wonder: Is she looking for attention because her parents have recently separated? Is she unusually anxious about something? Does she have some emotional problem that is not obvious? Finally, someone suggests to you that the child may have Tourette Syndrome.

WHAT IS TOURETTE SYNDROME?

Tourette Syndrome is a *neurological* disorder. Typically the symptoms of TS appear in childhood, and the most common time for the movements to begin is in the early elementary school grades. Thus teachers may be the first to observe the symptoms of TS.

There are four basic features which characterize the disorder. While these basic features of TS are necessary for diagnosis, there are other associated behaviors that are often seen in some TS patients. These will be covered further along in this publication.

1. The child with TS exhibits involuntary multiple motor tics. These tics may be sudden twitches of the head, shoulders or even the entire body; eyeblinks or rolling of the eyes; grimacing; or repetitive tapping, drumming or touching behaviors. For some children these movements take on a very complex pattern and may even include such functional behaviors as smelling objects or repeatedly turning lights on and off.
2. The second feature of TS is what are called vocal tics -- involuntary uttering of noises, words or phrases. These can include sniffing, throat clearing or repeated coughing, a variety of sounds or yells, laughing involuntarily, echolalia (repeating what others or oneself has just said) and coprolalia (saying socially inappropriate words). This last type of vocal tic is actually *not* very common, but seems to be one of the better known ones.

3. Another characteristic feature of TS is that the symptoms come and go. There may be times when the tics are very intense and others when the child may appear to be symptom free.
4. Finally, the symptoms of TS change over time. At one age a child may exhibit eyeblinks and sniffs. The next year he may have a shoulder shrug and make clicking noises with his tongue.

There is one particularly perplexing feature of TS. The tics are *involuntary*, yet, some children are able to suppress symptoms for seconds or longer depending on the individual. Thus a child with vocal tics may be absolutely quiet during church. Then, on the trip home, the tics "come out" with greater intensity and/or frequency than usual. This feature of TS can mistakenly lead people to believe that the behaviors are purposeful, or that the child doesn't really have tics at all.

WHAT CAUSES TOURETTE SYNDROME?

Until recently, people with TS and their families have suffered greatly because the reason for their unusual behaviors was not understood by the medical community. Most were misdiagnosed and told they had a problem caused by a variety of emotional disorders and the treatments they received were inappropriate. We now know that Tourette Syndrome is a *neurological* disorder with some associated symptoms that affect behavior. When teachers are knowledgeable about the symptoms of this disorder it is extremely helpful, for educators are often in the best position to observe a child's behavior over long periods of time.

It is now accepted that TS, along with some associated problems, is an inherited disorder. It is quite common to observe several members of a patient's extended family exhibit one or more of the motor tics or behaviors associated with the ailment. As with all genetically transmitted disorders, parents of these children often have painful guilt feelings about having transmitted this problem to their children. When talking with parents, it is helpful to be sensitive to this issue.

TREATMENT OF TOURETTE SYNDROME

When the tics are mild, a child may receive a diagnosis but no medical treatment. Acceptance of the fact that the symptoms and behaviors are not in the child's control and not purposely done to be "naughty" is sometimes enough to allow the child to function comfortably at home and at school. It may also be helpful to inform the child's peers and their parents about the TS, so they understand the reason for the tics. In some cases, however, the tics are disruptive and so distressing to the child that medical treatment is advisable.

Unfortunately there is no one "magic pill" that will both eliminate the symptoms and cause no negative side effects for the child. Many of the currently used medications can have serious side effects. Most commonly, these include weight gain, drowsiness and "slowed thinking". In addition, restlessness, depressive symptoms, school phobia or even severe allergic reactions can occur. Thus the medications that can help also have the potential of making the child drowsy or less able to focus and learn in school. In addition, while the medications reduce symptoms, they rarely eliminate them entirely. Thus, taking medicine usually involves a trade-off. Physicians and families will decide whether the benefits outweigh the problems. Input from teachers about the child's day-to-day classroom performance is critical to that decision process.

ASSOCIATED DISORDERS

For many children with TS, the tics are the only problems that may affect their adjustment in the classroom. Researchers and clinicians have observed that there is an association between TS and several other disorders which have a direct affect on behavior and learning. Many times it will be these *other* problems that present the biggest challenge in the educational setting.

Attention Deficit Hyperactivity Disorder

A high percentage of children referred for treatment of TS also have problems with attention, activity and impulse control. Many times these are the major interfering factors in the classroom. The treatment of children with the problem and TS is complicated, since there are questions about the effect of medications typically used to treat attention problems on the TS symptoms.

Obsessive-Compulsive Behaviors

Some people with TS also have obsessive-compulsive behaviors where they have an uncontrollable urge to complete certain rituals. They may feel compelled to redo their work many times because of tiny, barely perceptible imperfections. Some children may perform rituals such as 'evening up', i.e., tapping one arm the same number of times as the other, or performing some kind of touching or hopping ritual before entering a room. As they grow older, some may begin to believe that something bad will happen to them or others if this ritual is not performed. In the classroom, this type of behavior can sometimes make it difficult to complete work in an efficient way.

Learning Disabilities

A disproportionately high number of children treated for TS also have some form of learning disability. Visual-motor integration problems that make the completion of written work difficult are quite common, but depending on the individual child, the whole spectrum of learning disabilities might be seen.

Treatment of Associated Disorders

Depending on the severity, any one of these associated disorders may require treatment by appropriate professionals. Depending on the problem, medication, psychotherapy, special education placement and behavior modification may be used. (Behavior modification is used to deal only with specific behavior problems. There is no evidence that behavior modification can reduce the tics.) In addition, as with all children who have a chronic medical condition, children with TS may need some supportive counseling at times to help them deal with the social and physical impact of their symptoms. Proper diagnosis of each of these difficulties is needed before beginning any treatment. One should never assume that because a child has TS, he/she will always have these other problems. An informed teacher who can be involved in the total plan to help a child with TS is crucial to the future adjustment and well being of that child.

THE "TYPICAL" CHILD WITH TOURETTE SYNDROME

There is no "typical" child with Tourette Syndrome. Each youngster is unique. Children with TS reflect the normal intelligence curve. Some will be artistically or musically talented, others will be exceptional athletes. Some will be charming, with an excellent sense of humor, others will be serious and scholarly. A child with TS is just that -- a unique individual with some symptoms of a neurological disorder. The teacher who always sees *the child* and not just the *symptoms* is terribly important to the successful development of a balanced, positive self-image for the child with TS.

CLASSROOM MANAGEMENT OF THE STUDENT WITH TOURETTE SYNDROME

Dealing with Tics

For many students the only aspect of TS that will be evident in the classroom and at school will be the tics. The teacher's response to these tics and his/her reactions to other children's concerns about them can make the critical difference. It is the teacher and other school staff who are the adults most often involved in the life of a TS student. This involvement not only confers on them a serious responsibility, but also a great opportunity to have a positive and lasting impact on the TS child's adjustment and acceptance by his peers.

Classroom Tips

The following are important tips for dealing effectively with the impact of TS symptoms in the classroom setting:

1. In some cases the movements and noises can be annoying or even somewhat disruptive to the class. It is important to remember that they are occurring involuntarily. *Please do not react with anger or annoyance!* This may require patience on your part, but reprimanding the TS student is like disciplining a child with Cerebral Palsy for being clumsy. The child with TS who is scolded for his symptoms often becomes afraid of school or hostile toward those in authority. In addition, *you will be modeling the way to react to the tics for other children in the class. Moreover, if the teacher is not tolerant, others in the class will feel free to ridicule the child with TS.* Teachers are role models for their students. Acceptance and positive regard for the child with TS is "contagious."

2. Provide the child with opportunities for short breaks out of the classroom. A private place such as the health room is a comfortable setting to *let out the tics*. Some students with TS can and want to suppress their tics for a time, but eventually they must express them. There seems to be a buildup of tension that requires release. Time in a private place to relax and release the tics can often reduce symptoms in class. *These short time out periods may also enhance the child's ability to focus on schoolwork, because the student will not be using all his or her energy to suppress the tics.*
3. Allow the student with TS to take tests in a private room, so that the child does not waste energy on suppressing the tics during a very quiet time in the classroom.
4. Work with other students in the class and the school to help them understand the tics and reduce ridicule and teasing. School counselors, psychologists and representatives from your local Tourette Syndrome Association Chapter* can provide information and appropriate audio-visual materials for pupils and your colleagues.
5. If a child's tics are particularly disruptive, consider avoiding recitation in front of the class for a while. The student might be able to tape record oral reports, so that those skills can be judged without the added stress of standing before the class.

You should remember that the student with TS is as frustrated as you are about the annoying and disruptive nature of the tics. By being that child's ally in helping to cope with this disturbing disorder and working together with the child, family and other professionals, school can become a positive experience.

* *Call or write the National TSA for a local referral.*

Dealing with Writing Problems

A significant percentage of children with TS also have visual-motor integration problems; therefore tasks that require these students to see material, process it and then write it down are very difficult and time consuming. This problem also affects copying from the board or out of a book, completing long written assignments, neatness of written work and prescribed times for completion of written work. Even very bright TS children who have no trouble grasping concepts, may be unable to finish written work because of visual-motor impairments. *Sometimes it may appear as though the student is lazy or avoiding work, but in reality the effort to get the work down on paper is overwhelming to these students.*

There are a number of accommodations that can be made to help children with writing difficulties succeed in the classroom:

1. Modify written assignments by: having the child copy down and complete every *other* problem on a page of math; allowing the child to present a report on tape or orally rather than in writing; allowing a parent or another adult to copy down work or act as a "secretary" so that the pupil can dictate his ideas to facilitate concept formation. *It helps to focus on what the child has mastered and not the quantity of written work produced.*
2. Since the student with visual-motor problems may not be able to write quickly enough to get important information on paper, assign a "note-taking buddy" or "homework partner" who can use carbon paper to make copies of notes and assignments. The homework buddy should be a reliable student who can be called to make sure about assignments. Be sure to work this out discretely, so the child with TS does not feel singled out or different in yet another way.
3. On tests that have computer scoring sheets, allow the student to write on the test booklet. This helps avoid poor grades caused by the visual confusion that can occur when using the grid answer sheet.
4. Whenever possible allow as much time as needed for taking tests. Once again, consider giving tests in another room to avoid problems with the rest of the class.

5. Students with visual-motor problems are often poor spellers. Do not penalize for spelling errors, but instead, encourage proofreading and the use of a word processor with spell checkers.
6. Grade handwriting based on effort.

Students with TS seem to have special problems with written math. They can be helped by encouraging the use of manipulatives in teaching math and the use of a calculator to perform rote calculations. Using grid paper with large boxes or turning regular lined paper sideways to form columns can also help the child maintain straight columns when calculating.

These accommodations can make the difference between having a motivated, successful student, or one who feels like a failure and who will begin avoiding school work because success is never possible.

Dealing with Language Problems -- General and TS Related

Some TS children have symptoms that affect language. There are two types: language based learning problems that are common to other children, and language problems that are specifically associated with the tics of TS.

The following can be helpful when dealing with language processing problems that relate to general learning disabilities:

1. Provide visual input as well as auditory whenever possible. The student could receive written directions as well as oral ones, or have a copy of a lecture outline to follow while listening to instructions. Pictures and graphs that illustrate the text are usually quite helpful.
2. Give directions one or two steps at a time. When possible, ask the student to repeat the instructions to you. Then have the student complete one or two items and check with you to see if they have been done appropriately.
3. If you notice a student mumbling while working, try suggesting a seat where he will not disturb others. Sometimes quietly "reauditorizing" instructions or information to themselves can help students grasp and remember the assignment.

Among the language problems unique to TS children is the repetition of their own words or those of someone else. This symptom may sound like stuttering, but actually involves the utterance of words or whole phrases. Other students may exploit this problem by whispering or saying inappropriate things so that the TS student will involuntarily repeat them and get into trouble. You should be on the lookout for this difficulty.

In addition, this urge to repeat can be seen in reading and/or writing activities. Students may be unable to complete work because they 'get stuck' re-reading or rewriting one word over and over again. Sometimes this is called "looping." You can monitor the student to see when this occurs. When observed, the following can be helpful:

1. Have the student take a short break or switch to other work.
2. When reading, give the child a note card with a cut out "window" that displays only one word at a time. The student slides the window along while reading so the previous word is covered and the chances of getting stuck are reduced.
3. When writing, have the student use pencil or pen without an eraser or allow the student to complete that work orally. Occasional reminders to move on may help.

Your ability as educators to be flexible can make all the difference in the world!

Dealing with Attention Problems

In addition to learning difficulties, many TS children have varying degrees of attention deficit hyperactivity disorder (ADHD). As already noted, medical treatment for this problem in TS children is complicated. Even those who can be treated medically may still have some difficulty maintaining focus.

The following approaches may be helpful to the TS student with attention problems:

1. Seat the child in front of the teacher for all instruction and directions to minimize the visual distraction of other children.
2. Try not to seat the child near windows, doors or other sources of distraction, i.e., where reading groups meet.

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3. Give the student an "office" -- a quiet place to work. This could be in a corner, the hallway or the library. This place should not be used as a punishment, but rather a place the student can choose to go when focusing becomes difficult.
4. Have the student work in short intense periods with breaks to run an errand or simply wiggle in the seat. Change tasks frequently. For example, complete five math problems, then do some spelling, etc.
5. Contract for work to be done in advance. A specific number of problems should be finished by a certain reasonable time. Keep this realistic. Students with these problems shouldn't be given two or three sheets of independent work at one time. Short assignments with frequent checks are more effective.
6. With younger children, simple gestures, such as your hand on the student's shoulder, can be a helpful reminder to focus during listening periods.

DO TS STUDENTS NEED SPECIAL EDUCATION?

As already noted, the variability among TS children is great. Because of the association of learning and behavioral disorders, some will need special education services. These needs must be individually assessed by professionals familiar with TS. School personnel who may be providing those assessment services should consult with local experts on TS for information and guidance. The disruptive nature of the tics alone is not a reason to exclude a child from a regular classroom. Moreover, exclusion on this basis is illegal.

A CHALLENGE AND AN OPPORTUNITY

Educating a child with TS may present some interesting challenges. The more you know and understand about the disorder, the better able you will be to support that child's development. You have a tremendous opportunity to make a real difference in that child's life. Children with TS who can feel comfortable with their teachers and peers blossom in school and grow to become individuals who can develop their talents and make a positive contribution in life. Those children whose symptoms are misunderstood, or who are not supported in school, carry an enormous emotional burden. For the child, school is the arena in which one is tested. The child's sense of himself as competent, successful, likeable and valued is tremendously affected by school experiences. Your knowledge, support, patience, flexibility and caring are the best gift you can give a child with TS.

COMMON QUESTIONS FROM TEACHERS

- Q. I have read your ideas for helping the TS student in the class, but I have to deal with 25-30 other students. Where can I find the time?**
- A.** It does take some extra time and effort to implement these accommodations. However, the people who choose to become teachers do so because they want to help children grow and develop. That desire to help and advocate for children is particularly important to the TS student. In addition, if you think about all the time you already spend trying to help this child and dealing with his/her behavior, you may find that it will be worth the time to try some of the suggestions. In the long run, you may save time and reduce stress for yourself and the child by creating a situation where the child has a chance to succeed. Try to obtain help from other school personnel such as resource teachers, counselors, principals, school nurses and psychologists. Parents can help too by coming into the class to help with students or with clerical work that is a drain on your time.
- Q. What should I do if I think a child in my class has TS?**
- A.** It is important to bring this to the attention of the parents. It may be helpful to first contact the TSA or one of its local affiliates and request informational brochures to give to the parents. In addition, the TSA can provide names of knowledgeable medical professionals for the family to consult. It is important that the medical professionals involved know about TS, since it is still misunderstood among segments of the medical community.
- Q. If a child has TS, will the disorder necessarily worsen over time?**
- A.** Although we are just beginning to study the natural course of this disorder, we do have some information. TS is not a degenerative disorder. After the onset of tics in childhood, symptoms may worsen to a point and then change over time. However, most TS children and parents report that symptoms stabilize with a waxing and waning picture. Some proportion of patients have reported that symptoms improved or disappeared by late adolescence. So far, we cannot predict which students will have this improvement.

- Q.** There is a child in my class whose parents say she has TS. I have not observed all the symptoms they describe. Are they making it up?
- A.** No, they are not. As noted, children can suppress the tics for varying periods of time. Often they will do this in school to avoid ridicule. At home, where it is safe, the tics come out more intensely. Unfortunately, when the child suppresses tics in school, he is probably diverting his concentration from his studies. For suggestions, please see page 6, *Dealing with Tics*.
- Q.** A child in my class is on medication for TS. She often seems listless and has even fallen asleep in class. What should I do?
- A.** By all means let her parents know. The teacher is often the best observer of medication effects and problems. As part of the treatment team, your observations are invaluable. The child must be able to function effectively in school if the medication is to be considered a successful intervention.
- Q.** I can't always differentiate between tics and purposeful behavior in a child in my class. How can I tell?
- A.** You are in good company. Even a panel of experts on TS from around the world could not agree on what is a tic and what is simply problem behavior. Parents are often baffled by the same issue. The best thing to do is to talk with the student's parents and doctors to see if they can help you decide. In addition, discussion with the student may shed light on the issue. If the student reports a compulsion to do something, it may be TS. This does not mean you have to accept socially intolerable behavior. The student may need to work more closely with medical and mental health professionals familiar with TS to deal with those problems. In the meantime, however, anger and punishment are counterproductive. A safe place to let out those tics may be needed at times, but this accommodation is not the whole solution to the dilemma.

Q. I have a student with TS in my class. There have been some real problems dealing with his behavior and I need to talk with his parents frequently. Whenever I try to talk, however, they seem so angry at me and make it sound like his problems are my fault. What should I do?

A. Try to remember that the parents are just as frustrated about his problems as you are, and they are even more upset because it is their child. They view you as an expert on children and expect you to be patient and compassionate all the time. Although unrealistic at times, they hope you can accomplish what they cannot. In addition, they know their child is hurting and want to protect him from any stress or threat. Finally, parents of TS students often have found that others do not believe them or do not understand their child's needs. Therefore, they sometimes become strident and confrontational.

If this should occur, try to express your concerns and frustrations without placing blame on them or the child. Working as a team fosters cooperation. When necessary, ask to meet with the parents and a third party who can facilitate communication.

Q. Where can I get more information about TS?

A. The TSA has a catalogue of publications, and publishes a quarterly newsletter with accurate and up-to-date information on this disorder. The association can provide a variety of films and tapes that can be used for professional training or shown to school children to foster understanding thereby reducing stigma and ridicule for the TS child. Contact the national TSA office: Tourette Syndrome Association, 42-40 Bell Boulevard, Bayside, New York, 11361, 718-224-2999, or your local affiliate.

SUGGESTED RESOURCES

Other excellent sources of information about many of the types of problems that children with TS may encounter:

Silver, Larry, M.D., The Misunderstood Child, 1984, McGraw-Hill, New York, 212 pp.

Dr. Silver's book is an excellent overview of the various types of learning disabilities and their impact on the child's life. There is also an excellent section on Attention Deficit Hyperactivity Disorder.

Osman, Betty, No One to Play with: the Social Side of Learning Disabilities, 1982, Random House, New York, 170 pp.

This book illuminates the ways in which the processing problems of a learning disabled child can affect socialization.

Smith, Sally L., No Easy Answers: the Learning Disabled Child at Home and at School, 1980, Bantam, 326 pp.

This is another excellent overview of the multiple problems of the learning disabled child from the founder of the Lab School of Washington.

The FCLD Learning Disabilities Resource Guide: A State-by-State Directory of Special Programs and Services, The Foundation for Children with Learning Disabilities, 99 Park Avenue, New York, NY 10016.

This guide contains great information about parent support, informational and professional resources throughout the country. There is a good section on post-secondary educational resources for learning disabled students.

Promoting Successful Mainstreaming -- Reasonable Classroom Accommodations for Learning Disabled Students. Available, for cost, from:

Montgomery County Public Schools
Office of Special and Alternative Education
Carver Educational Center
850 Hungerford Drive
Rockville, MD 20851

This booklet is an exceptional resource for the classroom teacher. Possible accommodations in the regular classroom for learning disabled students were generated by special education personnel and then rated for "reasonableness" of implementation by regular classroom teachers. The suggestions are concrete and illustrated, when necessary, with good examples.

Rapoport, Judith, M.D., The Boy Who Couldn't Stop Washing: The Explanation and Treatment of Obsessive-Compulsive Disorder, 1989, Dutton, New York, 260 pp.

This fascinating book is a readable and informative source of information about the perplexing obsessive-compulsive disorder that affects a number of people with TS.

OTHER RESOURCES AVAILABLE FROM TSA

Davidovicz, Herman, Ph.D., "Learning Problems and the TS Child."

Hagin, Rosa, Beecher, Ronnie, Pagano, Gary, Kreeger, Henrietta, Effects of Tourette Syndrome on Learning, 1982, Raven Press, 6 pp.

Wertheim, Judy, Coping With Tourette Syndrome In the Classroom: An Informed and Sensitive Teacher Can Make a World of Difference.

Yohalem, Daniel, Dinsmore, Janet, 94-142 and 504: Numbers That Add Up to Educational Rights for Handicapped Children: A Guide for Parents and Advocates, 1984, Children's Defense Fund, Washington, D.C., 57 pp.

TSA Catalogue of Publications/Films/Videos

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The Tourette Syndrome Association is a national voluntary health organization dedicated to indentifying the cause, finding the cure, and controlling the effects of TS. Our programs of research, professional and public education, and individual and family services are made possible through the generosity of our donors.

For additional copies of An Educator's Guide To Tourette Syndrome, and additional information about TS, please contact the Tourette Syndrome Association.

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